PERSONAL HEALTH BUDGETS GUIDE

Implementing effective care planning
| Authors: Rita K Brewis, Gill Stewart and Jo Fitzgerald, with members of the Peer Network |
# Contents

1 **Introduction** .................................................. 3

2 **What is a personal health budget and what is its purpose?** ................................................. 5

3 **Evolution of personal health budgets and principles underpinning their use** ....................... 6

4 **Creating the local framework** ................................ 7

5 **The individual care planning process** .......................... 23

6 **Conclusion** ..................................................... 38

**Appendix 1**: Questions from workshops ...................... 39

**Appendix 2**: How peer support can help ....................... 42

**Appendix 3**: Risk enablement example .......................... 43
A personal health budget is an amount of money to support a person’s identified health and wellbeing needs, planned and agreed between the person and their local NHS team. Our vision for personal health budgets is to enable people with long term conditions and disabilities to have greater choice, flexibility and control over the health care and support they receive.

What are the essential parts of a personal health budget?
The person with the personal health budget (or their representative) will:
- Be able to choose the health and wellbeing outcomes they want to achieve, in agreement with a healthcare professional
- Know how much money they have for their health care and support
- Be enabled to create their own care plan, with support if they want it
- Be able to choose how their budget is held and managed, including the right to ask for a direct payment
- Be able to spend the money in ways and at times that make sense to them, as agreed in their plan.

How can a personal health budget be managed?
Personal health budgets can be managed in three ways, or a combination of them:
- Notional budget: the money is held by the NHS
- Third party budget: the money is paid to an organisation that holds the money on the person’s behalf
- Direct payment for health care: the money is paid to the person or their representative
The NHS already has the necessary powers to offer personal health budgets, although only approved pilot sites can currently make direct payments for health care.

What are the stages of the personal health budgets process?
- Making contact and getting clear information
- Understanding the person’s health and wellbeing needs
- Working out the amount of money available
- Making a care plan
- Organising care and support
- Monitoring and review
Implementing effective care planning

1 Introduction

“Personal health budgets allow people to move from a world where others know best, to one where their input is valued above all others but not in isolation from others. It is a way to allow the individual to be at the heart of the planning process, identifying with key health professionals the things that really matter to them and which allow them to lead a safe and fulfilling life”

- Personal health budgets peer network members, 2012

This paper defines a personal health budget, its purpose, and what is distinctive about this way of working with people. It describes the necessary preparatory work that needs to be done in order to develop a local framework that can enable best practice. The framework is important because the context within which individual care planning is implemented determines how effective any care planning process will be. The paper also includes a summary of the essential topics that must be covered and recorded during care planning, and describes how these discussions may best take place.

The function of any local framework for personal health budgets is to make sure that the person and the health professional both know what is expected of them, in order that the care plan can be created, authorised and successfully put into action. In this way, the framework will inform and shape each person’s individual conversation with their health team and will help support each professional’s shared decision-making.

Personal health budgets promote a shift in power and decision-making to enable a changed, more effective relationship between the NHS and the people it serves. The personal health budgets planning process is therefore not simply a document or a template. It is an active ongoing relationship and dialogue, with changes of role for individuals, health professionals and commissioners.

The central focus is similar to several other recent NHS initiatives such as “The Diabetes Year of Care”, “Shared Decision Making” and “Long Term Conditions Planning.” The aim is to improve the dialogue between an individual and their health professionals in order to create a combination of expert clinical knowledge with an individual’s unique direct experience and capabilities, their preferences, creativity and motivation.
At the heart of a personal health budget is a care plan developed in partnership between health professionals and people needing treatment.

In life threatening situations, people nearly always want to hand over control to skilled professionals. However, in recent years there has been a growing recognition that the effective management of chronic disease depends more on what individuals do, than professionals. There is an acknowledgement of the central role that individuals play in managing their own health, and personal health budgets are one important strand of this.

The Royal College of General Practitioners describe care planning as being about “making more effective the dialogue between the patient and the GP that is so vital to the care we provide every day, and changing the doctor-patient relationship into a doctor-patient partnership”. Care planning “will not only improve the quality of life for patients with long term conditions but will also give them more control, better health and better well-being”.

For individuals whose lives are highly dependent on health care, creating a plan that holistically addresses their health needs means that they can integrate health with other vital aspects of their life, such as work, education, housing, family and community. All of these interact with and impact on their health. A care plan that works well for key aspects of daily living will, by default then, support the effectiveness of someone’s health treatment.

Personal health budgets are consequently not only about money, and certainly not just about enabling choice. They draw on the skills, knowledge and natural motivation of people themselves, and combine that with the clinical expertise of health professionals and their understanding of the existing evidence base around different treatments.

---

1 Care planning - improving the lives of people with long term conditions, Dr Clare Gerada, Royal College of General Practitioners (RCGP) 2011.
2 What is a personal health budget and what is its purpose?

A personal health budget is an amount of money to support a person’s identified health and wellbeing needs, planned and agreed between the person and their local NHS team. Our vision for personal health budgets is to enable people with long term conditions and disabilities to have greater choice, flexibility and control over the health care and support they receive. The person with the personal health budget (or their representative) will:

- Be able to choose the health outcomes they want to achieve, in agreement with a healthcare professional.
- Know how much money they have for their health care and support.
- Be enabled to create their own care plan, with support if they want it.
- Be able to choose how their budget is held and managed, including the right to ask for a direct payment.
- Be able to spend the money in ways and at times that make sense to them, as agreed in their plan.

What is important, is that people with long term health conditions and disabilities get the chance to shape their lives by making the decisions about their health and wellbeing that matter most to them. Good care planning is about seeing the whole person in their whole life context. It’s about understanding how someone’s long-term health condition or disability impacts on the rest of their life.

If any of the key elements are missing, then the person is less likely to be able to make decisions about their health which matter most to them, and the personal health budget is less likely to be effective.

The crucial point is that a personal health budget enables self-determination, and a sharing of responsibility. Whilst it is almost impossible to achieve a ‘perfect’ life and illness can restrict people’s aspirations, personal health budgets can be used to support people in many different health circumstances to have increased control.

Personal health budgets planning is an inclusive approach. Under The Equality Act 2010 providers will need to understand how to make services accessible to all and meet different people’s needs across all protected characteristic groups. In the case of people who may not have capacity to make their own decisions, there can be ‘best interest decisions’ guided by the principles of the 2005 Mental Capacity Act. It enables people with fluctuating health conditions to plan for a time when they may not be able to discuss options or make their own decisions.
Implementing effective care planning

The concept of a personal health budget and the associated shift in power and shared decision-making has a dual heritage, evolving both from the NHS and from the movement for change driven by people themselves. Campaigners in disability rights, and “survivors” of mental health services, “expert patients” and family carers have long been calling for the right to an independent and fulfilled life as part of their local communities, with as much control over their treatment and ongoing support as they wish to take.

Concurrent with this movement for change driven by people themselves, the NHS has a number of initiatives focused on the broad personalisation agenda. For example, the Royal College of General Practitioners describe care planning as a powerful way of creating an environment that helps clinicians to support self-management:

“When patients self care, and equally feel supported in doing so - they are more likely to have greater confidence and a sense of control, to have better mental health and less depression, and to reduce the perceived severity of their symptoms, including experienced pain.”

Similarly, the Health Foundation, when summarising the evidence for self-management, describes “a fundamental transformation of the patient-care giver relationship into a collaborative partnership.”

There can then be seen to be a coming together of NHS initiatives and personal drivers for change, which gives the potential for significant progress when the purpose and underpinning principles of personal health budgets unite. The purpose of a personal health budget is to ensure that people with long term health conditions and disabilities have the chance to shape their lives by making the decisions about their health and wellbeing that matter most to them.

The principles underlying personal health budgets are as follows:

- They must uphold NHS values and be free at the point of delivery and not depend on ability to pay.
- They must support safeguarding and quality.
- They must support the tackling of inequalities and protection of equality.
- They must be voluntary.
- They must support the making of decisions as close to the person as possible.
- They must support working in partnership.

2 Care planning – improving the lives of people with long term conditions, RCGP 2011.
3 Helping people help themselves, Health Foundation 2011.
4 Personal health budgets: first steps, Department of Health (the DH) 2009.
The message from all the sites involved in the pilot process is that it is critically important to get the groundwork right when offering people personal health budgets. Making personal health budgets work well depends on people making significant changes to their thinking, feeling and behaviour. This is a process that cannot be rushed and that requires a clear and mutually understood common purpose and framework.

Personal health budgets enable people to create their own effective and efficient health plan based on a new understanding of what money is available to them, both at the outset and over time.

“The transparency about the money is really empowering and shifts the conversation”
- Continuing Health Care Commissioner in Oxfordshire

What are the things any of us would want to know if we were presented with an opportunity to do something new and different from our usual experience? Thinking about this question is the most helpful way to start to consider how to define the “deal” between the NHS and an individual, outlined in the local framework.

Personal health budgets offer a new relationship or contract: a sharing of power and responsibility, a shifting of control and decision-making towards the person and an opening up to new flexible ways to achieve health outcomes within the context of someone’s whole life. It is not “something for nothing” and it is not “anything goes”, because it has clear and simple rules. At its best, the process of personal health budget planning is a well thought-through, carefully considered and simple approach.

This document is based on learning from pilot sites where all the people involved in personal health budgets came together to share their understanding of the local processes. People with budgets, clinicians, personal health budget brokers and health and social services commissioners discussed key questions about personal health budgets, and shared their perceptions and experiences. (The questions from the pilot site workshops can be found in Appendix 1).
Feedback from these events and national learning has demonstrated that it is crucial to have an explicit shared understanding of the local framework before people start to discuss and create their care plan. Anecdotal evidence suggests that the following elements are essential to the development of a framework within which effective care planning can take place:

- Develop a peer network and involve everyone from the start.
- Clarify the purpose and principles.
- Be clear about all aspects of the money: when and how a budget is offered; how much money is being allocated to the individual; the flexibility of spending the money; and what the monitoring and review process will be for the money.
- Develop and provide information, support and training.
- Agree a local approach to choice, safeguarding and risk enablement.
- Agree the criteria that a care plan must meet for authorisation/sign-off.
- Agree the process of authorisation and appeals.
- Agree how care plans will be monitored and reviewed.
- Create a strategic commissioning feedback process to inform market development.
- Create a local communication strategy and a plan for workforce development.

Develop a peer network and involve everyone from the start

“Don’t try and figure it all out alone first”
- NHS Continuing Healthcare manager, pilot site

Since care planning with a personal health budget is about a change in the relationship between the person and their clinician, it is essential to involve both these groups in the development of the new ways of doing things. Other people also need to be involved: family carers, commissioners, healthcare and social care managers, finance managers, administrators, and voluntary sector providers, to ensure that the framework for care planning meshes with the wider systems within the NHS, the local community, and the Local Authority.

Perhaps one of the best ways to embed cultural and professional change in a complex ‘whole system’ is to aim to engage people from each key part of that system, so that everyone can help develop and thus have ownership of any changes. Discussion and involvement by many different people means that everyone’s creativity is engaged, new ideas are challenged and made more robust through discussion, and therefore resistance to change is avoided later on in the process.
Furthermore, inviting people with direct experience of health care treatment as equal participants with health professionals and commissioners, demonstrates that their views are valued and respected and that reflects one of the central foundations underpinning personal health budgets. Inviting social care staff to be part of developments indicates the wish for a joined up, integrated approach, which reinforces working with an individual as the focus, rather than the different service systems and organisations.

Some of the most striking learning from the care planning process work-stream was the realisation of how different people’s perceptions and experiences were when everyone was brought together. It was apparent that well-intentioned policies can have unintended consequences which the NHS can be unaware of, if collaboration and feedback systems are not securely in place.

The best chance of benefitting from an essential feedback loop is by keeping connected with people’s everyday real life experience of accessing health care and using personal health budgets. However, the NHS is an institution with its own language, culture and customs and it will take time and practice for people who are not accustomed to these entrenched mechanisms to be able to take part in discussions. Investment in developing people’s skills and confidence to fully engage in the development of the local framework for care planning will yield dividends as expressed by a manager of a pilot site:

“Patient involvement in developing personal health budget systems will ebb and flow as people’s conditions fluctuate, so it’s ok to start with a very small group of people and build a broader group over time- and invest in that group of people”

- NHS Continuing Healthcare manager, pilot site

People from different perspectives starting to work together can be complex. Trust builds slowly and gradually. If people feel more confident, they are able to respectfully challenge each other. None of this happens without good leadership acting in a coordinating role to nurture and support this process of development.

To ensure that peer input happened as an integral part of the personal health budget pilot programme, the Department of Health invested in a part time coordinator’s role and also funded people’s travel expenses so that they could link up nationally, face to face. The Department of Health also recognised the need for people to meet together as a separate group initially, and supported that happening so that people could gain knowledge and confidence before joining the pilot work-stream groups. For local developments, some investment by commissioners will also be necessary.

Jo Fitzgerald, the leader of the personal health budgets peer network has written the following summary description of how peer support can best be enabled, and why it is important.
“We have clearly established that involving peers in the development of personal health budgets is crucial. Peer to peer input fosters confidence. We often talk about cultural change in the NHS and how the way people think and behave needs to adapt to realise the vision we all share for improved outcomes for people. The same needs to happen for individuals and families if they are going to embrace the opportunity to take more control over their health and wellbeing. They need to believe that change can happen.

“The most powerful way to communicate new possibilities is for peers to talk to each other. There is an innate trust between individuals and families with shared experiences. A robust strategy for the dissemination of accurate and useful information is vital along with developing a regular feedback loop. This can be done in a number of ways but one of the most robust is to involve people at every stage of development by creating a peer network.

“There is a lot of literature about involving people in the development of services but few examples of where it has worked well. The issue is often the ‘way’ people have been involved. Too often, people with direct experience are invited to participate when important decisions have already been made. There’s a tendency to believe that clear plans need to be in place and a strategy agreed before people with direct experience can be invited.

Whilst involving everyone at the beginning may feel uncomfortable, that’s exactly when it should happen. Ensuring that everyone is on a ‘level playing field’ gives you the best chance of success.

We’re all learning about personalised approaches so the best way to make things work is to involve the people who have the highest vested interest in making things work – the people who will ultimately benefit from developments.”

**Clarify the purpose and principles: What is this all about?**

It is necessary for health staff to be able to explain to people what a personal health budget is, and what it is for, in a straightforward and simple way and to dispel any misunderstandings or fears. When setting up the personal health budget framework, and when implementing the care planning process, the most helpful guiding principle to underpin all decision-making is to keep remembering the purpose of the budget:

“You always need someone in the group to say we need to go back to what we are trying to achieve”

- Continuing Health Care Commissioner in Oxfordshire

It is apparent from work that has taken place so far, that it takes time and numerous conversations to build knowledge and consensus about the purpose and use of personal health budgets. People can find it helpful to be encouraged to ask questions as fresh issues arise, and to be supported to constructively debate the shifts of relationship being developed, and what this means to them personally and professionally.
Once a group of key people locally have a shared understanding of the purpose and distinctive characteristics of a personal health budget, they can then work out with the aid of national learning and emerging policy, what their local framework is going to be.

**Be clear about the money**

**When and how a budget is offered and managed**

People want the opportunity of taking up a personal health budget to be available at the time that is right for them. People’s confidence and readiness to consider options will vary. Offering a personal health budget shortly after someone has been through a health crisis is unlikely to be helpful. The framework needs to include how and when personal health budgets will be offered. Staff should be ready and able to work with people at the time when the person is confident enough and ready to take more control, and when they are willing and have the energy to put in the work to make taking more control happen.

A personal health budget does not have to be offered and taken up at one single point in time and all at once. People may wish to change one small part of their care first. A personal health budget is thus not an “all or nothing” offer and it is not obligatory. It is voluntary and a choice, so people can be assured that they do not have to change anything immediately. They may want to take time to think about what they might like to be different, or to prioritise just one part of their treatment/support. People can have a mix of NHS services and some things that they buy for themselves with their personal health budget. It is also fine to keep everything just as it is. Many people highly value their NHS treatment and want it to continue unchanged.

All of this means that people need to be able to choose to take control of a budget, and increase their take-up of responsibility, at a pace that feels comfortable for them. They may choose not to manage the money directly, but use another organization or person to hold it on their behalf, whilst retaining the freedom to choose how it is spent.

To ensure equity of access to this new way of achieving health outcomes, there must be a range of ways available to hold and manage the money, not solely access to a direct payment. This is because many people may not want, and some may not have capacity to use direct payments.

**How much money**

This paper starts at the point where someone has been assessed as entitled to have some on-going health needs met by the NHS and an indicative budget has been allocated. It does not seek to describe how this process should happen. However, it would be incomplete without acknowledging the very real and challenging issues presented when considering how best to calculate appropriate budgets that can be offered instead of services.
For example, the NHS is currently in the process of developing a fuller understanding of what services actually cost because up until very recently, many services have been commissioned through large block contracts.

Understanding costs and discussing them with individuals can feel unfamiliar within the NHS, and people can be surprised by the cost of services they have been used to working in, or receiving treatment from. Once people do have this information, there is growing evidence that people are thoughtful about how to make the money work the best for them, and seek to get good value for what they are aware is essentially public funding. Making a plan with clarity of what money is available from the start allows for a realistic appraisal of options and encourages creativity and innovation.

To support implementation of personal health budgets a paper has been produced that describes the thinking so far on how personal health budgets might be calculated when someone is eligible for NHS Continuing Healthcare funding. There will also be a paper on approaches to making budgets available to people with long term conditions.

**Flexibility of spending the money**

People will need to know what their budget can be spent on and what is excluded. This can be simply communicated by letting people know the short list of nationally excluded criteria, and that everything else may be tried as a means of achieving personal health outcomes, provided the local framework for support planning process is followed. The list of exclusions, subject to updated learning from the pilot programme are as follows:

- Emergency or acute services.
- The majority of primary care services (including visits and assessments of GPs).
- Anything illegal.
- Gambling.
- Debt repayment.
- Tobacco.
- Alcohol.

The care planning process will have involved the person in considering what is important to, and for, them, their ideas and what they are willing to commit to, along with support and information from the health professional about what might have proved useful for others and what research evidence suggests too. See further on in this guide for more about this. When considering flexibility of spend it is important to remember that currently, whilst there are NICE approved treatments, there are currently many treatments and services provided by the NHS whose efficacy varies person to person.

“There are no treatments that are 100% reliable and 100% side effect free and there are very few clinical situations where there is just one course of action that should be
followed in all cases. In circumstances where there are a number of options leading to different outcomes and the “right” decision depends on a patient’s own particular set of needs and outcome goals, the condition is said to be “preference sensitive” shared decision making for these conditions should be informed by the available evidence and by the patient’s wishes, needs and preferences.”

- Coulter and Collins, 2011

“Commissioners will need to think beyond block commissioned services and give people the opportunity to work together with the expert professional advice and knowledge of their local health team. Together, they can find creative, efficient and effective solutions, drawing also on peer knowledge and experience. PCTs should be careful not to exclude unusual requests without examining the proposal on a case-by-case basis - these may have significant benefits for people’s health and wellbeing.”

- The Department of Health

There is evidence that highlights that when people are given choice and control it leads to better health outcomes. For example, in a large randomised control trial “the effect of giving a choice of formats for a programme of heart disease management improved physical and psychosocial functioning.”

A personal health budget holder vividly describes how empowering it is to be given control:

“If someone else had chosen the exact things stated in my budget, it wouldn’t have had the same impact on my life; it’s the fact I’ve thought about and chosen for myself. I’ve taken control and purchased back, if you like, the self-worth I thought I’d lost forever”

- Personal budget holder 2012

Money monitoring and review

Irrespective of how people choose to hold and manage their budget, they will need to know the other practical aspects of money management such as:

- The records to keep.
- When and how the money will be monitored.
- What happens if a mistake is made.
- How much money may be set aside for emergencies or fluctuations in their condition.
- How the budget will be reviewed if needs change.
- What support is available if the person takes the money as a direct payment.
- Information about the full range of third party options available.

Some of the most important learning to bear in mind when agreeing this part of the framework is the need for trust, and proportionate light-touch monitoring of the money. This needs to be integrated within a simple process for monitoring and reviewing health outcomes.

8 Direct payments for Healthcare: Information for pilot sites, the DH July 2010.
“The PCT must undertake on-going monitoring of how the direct payment is being used and the health condition of the person. Reviews should be light-touch, and should place as few burdens on people, representatives and nominees as possible.”

- The Department of Health

Develop and provide information, support and training

It is important for someone to be able to choose whom, if anyone, they would want to support them to write their care plan. This is a critical role. Pilot sites have found that some people are happy and comfortable to plan on their own, particularly when they are given clear information about what is expected of them. But when planning for the first time, many people will want to talk things through with someone else; preferably someone with whom they feel comfortable and someone who they believe has an understanding of their situation. This may be their healthcare professional but some people may prefer an independent person to guide them through the process and liaise with the relevant parties. As with each aspect of personal health budgets, enabling choice and not assuming one option will suit everyone, is the most useful and fruitful approach.

Not everyone, including some health professionals, will feel comfortable in this facilitative role. Staff may welcome some additional training and support in facilitation. The personal health budgets toolkit will include a paper on preparing the workforce to offer personal health budgets.

It is important to bear in mind that people with long term health conditions may themselves put their own constraints on what they will talk about. They may find it hard to disclose what is not working for them, feel that they ought to just be grateful, and be fearful of losing services that they value. This is where peer support can play a big part. Pilot sites have made a range of support options available to people, including independent brokerage. Some are also beginning to build peer support into their care planning process as an effective and sustainable way of providing care planning support. Many people are willing to offer support to one other person reciprocally for help that they themselves have received from another person. Peer support can help in fundamental ways with the critical elements of the process (see Appendix 2 How peer support can help).

Agree local approach to choice, safeguarding and risk enablement

Choice

Whilst personal health budgets can offer creative choice, they can also offer far more than this:

9 Direct payments for healthcare: Information for pilot sites, the DH July 2010.
10 www.personalhealthbudgets.dh.gov.uk
“Personalisation recognises that the individual has a whole life, and their own “Real Wealth” - that is: someone’s strengths, knowledge, resilience, community contacts, personal relationships and resources. Personalisation tries to enable services to work with the fabric of that whole life”

- Alakeson and Duffy, 2011

In this way personal health budgets are far more than simply a way to increase choice. They can amplify the effective use of the money through combination and integration with someone’s internal and external resources e.g. their motivation and relationships.

People need to feel that it is possible for useful change to happen and hopeful that their day-to-day lives can be improved. This remains necessary even when someone has a deteriorating health condition or is nearing the end of their life. Having the chance to hear about real life examples of what others have done differently, and talking with peers are two useful ways to share creative thinking and generate new possibilities. It will also be necessary to work with local providers and specialist and mainstream community services, to ensure that people can access and buy what they are looking for.

Safeguarding and risk enablement

Before recent personalised care planning initiatives in the NHS, such as “The Diabetes Year of Care”, “Shared Decision Making” and “Long Term Conditions Planning”, the people with most to lose if things went wrong were sometimes the very ones excluded from discussions about risk. Management of risk and responsibility for safeguarding were seen as the responsibility of professionals. When people use personal health budgets, they plan on how to use their budgets creatively, to tailor their care and support to improve their situation and to achieve their personal health outcomes. Part of that planning process must include weighing up benefits against any possible risks of particular aspects of their care plan.

People will continue to want to discuss the merits of different treatment options with their clinicians. When considering a choice of care providers and third party organisations, they may also want to seek information more widely, and to consult with other people (for example with friends they trust), and perhaps with people who have similar health conditions.

Some people will use their budgets to continue to purchase traditional services that they find work well for them, and some people will want to use a personal health budget to meet their health outcomes in different ways. It will not be possible to simply rely on existing regulations and protocols to manage risk, and it could plausibly be argued that the regulations were not working well enough in the ‘old’ system. NHS Commissioning organisations will have to devise processes that balance protection of the person and the organisation with the individual’s right to self-determination.

11 Health efficiencies - the possible impact of personalisation in healthcare, Vidhya Alakeson and Simon Duffy, Centre for Welfare Reform October 2011.
People already have the right to make choices about their care and treatment. It is not possible, nor helpful to try to eliminate all risk. In “Making Shared Decision Making a Reality”, the authors emphasise how important it is to involve people in managing risk, particularly “when it comes to clinicians ‘trusting’ patients to take a course of action outside the consulting room, (taking medication for example). In this case, it is tempting for clinicians to ‘tell’ patients what to do in order for the clinician to feel that they are in control of the risk (in this case the risk of non-adherence). For many clinicians it is counter-intuitive to support patients to understand and manage risk for themselves, yet this is precisely the approach that supports adherence.”

Part of all best practice care planning will be a discussion about possible risks that might be incurred by the proposed use of the personal health budget and how these can be minimised to an acceptable level. Decisions will take into account the outcomes that the person is seeking and bear in mind their particular circumstances, lifestyle and beliefs.

The Department of Health and partner organisations recently published papers to support “No Secrets” guidance, which contains materials for health service managers, practitioners and NHS commissioners. This set of papers describes how good practice safeguarding principles can guide health services to safeguard adults. It is clear however, that the NHS cannot dictate to the person the care or treatment that they receive, and that risk choices are a personal issue.

“It is not possible, nor arguably desirable, to eliminate risk. Empowerment in safeguarding involves risk management that is based on understanding the person, understanding the autonomy of the person and how they view the risks they face. There may be risks the person welcomes because it enhances their quality of life and risks that the person is prepared to tolerate and those they want to eliminate.

Health services have a duty to safeguard all patients but provide additional measures for patients who are less able to protect themselves from harm or abuse.

“Safeguarding adults” covers a spectrum of activity from prevention through to multi-agency responses where harm and abuse occurs. Multi-agency procedures apply where there is concern of neglect, harm or abuse to a patient defined under “No Secrets” guidance as ‘vulnerable’.”

- The Department of Health

Safeguarding adults is an integral part of patient care. Duties to safeguard patients are required by professional regulators, service regulators and supported in law.

Empowering approaches to safeguarding

Duties to empower people to make decisions and be in control of their care and treatment

12 Making shared decision making a reality, Angela Coulter and Alf Collins, Kings Fund 2011.
13 Safeguarding adults: The role of health service practitioners, the DH 2011.

- Patients have the right to make choices about their care and treatment and this includes making decisions about their safety, even where those decisions may seem unwise to others.
- Empowerment means enabling the person to control decisions about their care to an extent to which they are able.
- Any actions that do not have the person’s full and informed consent must have a clear justification, be permissible in law and the least restrictive of the person’s rights to meet the justifiable outcome.

The five principles of the Mental Capacity Act

1) A person must be assumed to have capacity unless it is established that he/she lacks capacity. Assumptions should not be made that a person lacks capacity merely because they appear to be vulnerable.

2) A person is not to be treated as unable to make a decision unless all practicable steps to help him/her do so have been taken without success. Empower patients to make decisions about managing risks e.g. use communication aides to assist someone to make decisions; choose the optimum time of day when a person with dementia may best be able to evaluate risks.

3) A person is not to be treated as unable to make a decision merely because he/she makes an unwise decision. Patients will wish to balance their safety with other qualities of life such as independence and family life. This may lead them to make choices about their safety that others may deem to be unwise but they have the right to make those choices. For people who are deemed to lack capacity to make their own decisions the following principles must be enacted:

4) An act, or decision made under this Act for or on behalf of a person who lacks capacity must be done, or made, in his/her best interests. Best interest decisions in safeguarding take account of all relevant factors including the views of the patient, their values, lifestyle and beliefs and the views of others involved in their care.

5) Before the act is completed, or the decision is made it must be considered whether the purpose for which it is needed can be as effectively achieved in a way that is less restrictive of the person’s rights and freedom of action. Where a person lacks capacity to make a decision, any use of restriction and restraint must be necessary and proportionate and to prevent harm to that person. Safeguarding interventions need to balance the wish to protect the patient from harm with protecting other rights such as right to family life.”
The Mental Capacity Act 2005 provides a statutory framework for acting and making decisions on behalf of people who lack capacity to make particular decisions for themselves, or who have capacity and want to make preparations for a time when they may lack capacity in the future. It sets out who can act and take decisions on behalf of a person who lacks capacity, in which situations, and how they should go about this.

The Act sets out five statutory principles that must be adhered to. When thinking of this Act in terms of personal health budgets, the majority of people are likely to have capacity to make their own decisions, or to forward plan for a time when they may lose that capacity.

Agree the criteria for sign-off

In order for a person to be able to write their care plan, and for their health team to authorise it, there needs to be a straightforward summary of what it must contain and this must be shared with the person. Experience suggests that the following key criteria are necessary in order to authorise a care plan.

Criteria for authorising a care plan

The plan must:

1) Show who the person is, with their strengths and skills, and their personal social context, as well as their health needs. If the person lacks capacity to make their own decisions the plan must show how this decision was reached and identify who will speak on their behalf.

2) Describe what is working and not working from their perspective.

3) Detail what is important to the person and what is important for their health.

4) Identify and address any risks and how they will be mitigated to an acceptable level, including a contingency plan for if things go wrong, and a point of contact in health services.

5) State the health outcomes to be achieved and how it is proposed that those outcomes will be achieved.

6) Describe in broad terms how the money will be held and managed and show how it will be used to achieve the outcomes.

7) Have an action plan that details who will do what and when to ensure that the plan is carried out.

8) Include the name of the person’s care coordinator.

9) State how and when the outcomes, and the money, will be monitored and reviewed. This will include describing how people will know the plan is going well, and how people would know if things were going wrong.

More information on The Mental Capacity Act can be found at: www.dh.gov.uk/en/SocialCare/Deliveringsocialcare/MentalCapacity/MentalCapacityAct2005/index.htm
Agree the process of authorisation and appeals

The plan may be written in many different styles but it must include the key criteria (previous). A best practice plan will have a clear thread running through it showing how a person’s health needs link to an agreed set of outcomes, and show how the budget will be used to meet those outcomes. It will detail who the person is and what matters most to them, as well as what matters for their health and wellbeing. It will describe how risk issues have been identified, discussed and addressed. The plan can often be signed off by the health team because they are often the people who know the person best. Ideally, sign-off is delegated to a person that is as close to the individual as possible, in line with the NHS principle:

“Personal health budgets must support the making of decisions as close to the person as possible”. In this way, it is a decision made by health professionals who are closely involved and know the person and their unique family and community context”.

- The Department of Health

To support this happening, risk enablement processes can be very useful, so that no single professional feels that they must make all the decisions alone. These processes allow health professionals, individuals and family members to call together a small, consistent group of people familiar with health risk enablement, to consider a particular risk – should they wish to do so. The group agree how best it will be managed and record that learning. Over time, a log of risk enablement strategies are gathered that can then be a helpful local resource, and a source of national good practice. (See Appendix 3: Summary terms of reference of a risk enablement group.)

Funding panels can be seen to become unnecessary once criteria for a good plan have been made explicit; and once staff have had sufficient training and are confident and trusted to make sure that those criteria for sign-off have been met. Confidence is supported when staff have a back up risk enablement group to call on if they wish to.

“Experience has shown us that Panel meetings are not efficient. In some cases the cost of the attendance of the panel members is more than the budget itself. Instead we have found that devolving responsibility to the key-workers and the service users themselves is a better way of delivering safe and appropriate personal health budgets”.

- Project Manager Norfolk

Authorisation processes will need to respect the fact that peer network members are clear that they expect to be present when all decision-making takes place, along with whomever else they may wish to support them. If a plan cannot be signed off, then clear guidance for how it needs to be amended should be given.

15 Personal health budgets: first steps, the DH 2009.
Appeals

It is necessary for all parties to know what will happen if there is disagreement, and to have a clear process of appeal.

Agree and describe how care plans will be monitored and reviewed

In the UK, long term conditions such as diabetes and heart disease account for 70% of spending in the NHS. By their very nature, conditions like these require day-to-day management to prevent the condition worsening and a subsequent emergency hospitalisation. This task falls far more on individuals and their families than health professionals.

“If there are 8,760 hours in a year, the average person with a long term condition in the UK spends no more than three or four hours a year with a health professional - that is less than 0.05% of the year.”

- Hannan, 2010

Taking this view into account then, it seems likely that monitoring and reviewing processes must be evolved to match the fact that for many people they must regularly self monitor and act to address changes in their health condition. A well-written support plan will include information from the relevant health professionals about the person’s particular critical health factors, and how these must be addressed. The plan will also state what actions to take when necessary to address a change in these critical factors, and who to turn to if things go beyond a specified safe limit.

The formal review of an individual’s personal health plan will be a summary reflection of the micro reviewing and monitoring that is taking place by the individual who holds this responsibility every day. The purpose of the review should be clear and explicit and planned to make the best use of everyone’s time. There should be no surprises, since through the year the person can alert their health professional and call a review if there are any critical incidents or crises. Similarly, a proportionate and simple monitoring of the budget will have been on-going through the year, and can be summarised for review.

N.B. Department of Health regulations for personal health budgets direct payments state that there must be a care coordinator to fulfil the following functions:

- Manage the assessment.
- Ensure people have an agreed care plan.
- Manage the review and monitoring process and liaise between the NHS commissioning organisation and the person receiving the direct payment.
- When someone is not receiving the budget as a direct payment, having a named point of contact to carry out each of these functions is equally valid and necessary.

16 More information on The Mental Capacity Act can be found at: www.dh.gov.uk/en/SocialCare/Deliveringsocialcare/MentalCapacity/Mental CapacityAct2005/index.htm
Strategic commissioning feedback to inform market development

It will be helpful to use the individual review process to collect information and on-going feedback on the use of personal health budgets, rather than use a separate system or piece of research. The review process should capture what is working and not working in terms of outcomes, money and the process as a whole. Aggregating the information gathered through each individual review of outcomes and process will give vital information for strategic planning and market development.

“Every decision made in a personal care planning conversation is also in effect a micro commissioning decision. Capturing this information and aggregating it can inform the macro commissioning strategy”

- Coulter and Collins, 2011

Develop a local communication strategy and workforce development plan

Once a group has worked together to create the key elements of the local framework for personal health budgets, they will need to consider carefully how best to communicate this. Information will need to be made available in a range of formats. To support local workforce planning, the Department of Health personal health budgets toolkit will publish a paper on Workforce Development.17

17 Making shared decision making a reality, Angela Coulter and Alf Collins, Kings Fund 2011.
Implementing effective care planning
The central focus of personal health budget planning is on improving the dialogue between an individual and their health professionals in order to create a synthesis of expert clinical knowledge with an individual’s unique, direct experience and capabilities, their preferences, creativity and motivation. At the heart of a personal health budget is a care plan developed in partnership.

A care plan is a record of the discussions and agreements between the person and their health team. For people using a personal health budget it will specifically include their health needs, the outcomes they want to achieve, how they intend to use their budget to do this, and the name of the care coordinator responsible for managing the care plan.

The following section of this paper outlines how this process may best take place. These are the essential topics that must be covered and recorded during care planning:

- Accessing the framework information.
- What is working and not working.
- What is important to me and for my health.
- Priorities and outcomes.
- Action planning.
- Sign off.
- Review.
1) **Accessing the framework information**

Before starting to plan, people will need to have been given clear accessible information about what a personal health budget is, what its purpose is and what the “deal” is (i.e. all of the local framework information, including: how much money is in their personal health budget, the choice of ways to hold the money; the choice of and range of support for planning; information about what could be possible; etc.). Capacity issues will also need to be addressed in the initial stages of the process.

This is a lot of information for someone to take in, and this first stage needs to be given sufficient time. Staff need to explore people’s understanding, and give space for questions and clarification. Sending a leaflet or directing someone to a web site is unlikely to be sufficient, though can be a helpful part of a broader approach. Linking people with others who have a personal health budget already in place can be particularly helpful, both in person and via virtual links and forums. For example: www.peoplehub.org.uk.
2) What is working and not working?

Initially, the opening conversation needs to seek to build a trusting relationship and allow people space through which to explore what is working and not working in their life, related to their health. People may need to explore this with peers, to begin to move from a passive acceptance of everything remaining the way it is, to a realisation that things could change. For example, if a parent carer has never been able to go out for the day with their child because the shift of agency staff ends every day at 2pm, they may not appreciate initially, that through using a personal health budget to organise the shift times differently, they could enable their child to have the same opportunities as other children and to live a more flexible life.

For people with long term health conditions, their health needs are often woven into every aspect of their life, so there is little need to worry that people will talk about random or irrelevant things when they identify what is working and what is not working well in their lives. This part of the planning process gradually starts to build a picture not only of health needs, but of who the person is and how they want to shape their life.
by making the decisions about their health and wellbeing which matter most to them.

“Previously, the vital question of how the individual would like to live their life was never asked. There was little planning around the individual and often the debate would be around generic symptom management, and too often on the professional assumption that any other way would be too costly, too risky or too onerous”
- PHB peer network member 2012

The point at which a health professional’s views are incorporated into the planning process is really important. The health professional’s view is not put in at the very beginning nor at the very end. There needs to be a space given first for exploratory discussion, active listening and respectful questioning and reflection in order to find out the most important things which are working and not working from the person’s perspective.

3) What is important to me and important for my health?
It is vital to consider together, within those things which are working and not working, what is important to the person in terms of what matters most to them, and also what matters for their health. The person in question is the only one who can know what matters to them, and they will also (unless newly diagnosed) have a good idea of what is important for their health. The professional can then add their expertise once the person has identified what is important to them with regards to their health needs.

In thinking together about what is important to and important for someone, health professionals can helpfully contribute their expert knowledge about the specific “important for” information. For example, the person may be aware that they need to keep their blood sugar or oxygen saturation at a certain level, and so the professional can give specific detail and advice about how to monitor and maintain the correct level for their particular illness, age and context. Health professionals also play a vital part in helping people to explore really difficult issues around loss, and adjustment to a different life after accidents or strokes, or following a life limiting diagnosis.

So it is at this point where the health professional can most usefully begin to input their knowledge, ideas and expertise.

“One thing that some of our patients have told us was really helpful was to advise them to have the questions in the toolkit (Personal health budgets information) e.g. What is important to you and for you, What is working well, what isn’t working well etc. out on the side so that they could jot things down as they discussed them with family, friends and different health professionals. This preparation helped them to write the plan but also to think of ideas for meeting outcomes that maybe they wouldn’t have thought about on their own”

- Project Manager Northamptonshire

A great planning process will lead to a plan that integrates what matters most to someone with what matters most for their health, because it is that interaction and joining together of best clinical practice with someone’s own motivations and creativity that leads to plans which are:

- Acted on and not ignored.
- A live participative process and not a “prescription”.
- Which make best use of both professional and individual knowledge and ideas.

Risk enablement

It is also in this part of the conversation that any risks can be identified and addressed. When planning with a personal health budget, risk and responsibility are openly discussed and can be shared. If a person wishes to have more power and control then there is an expectation that they will begin to share more responsibility for the management of their health condition. As stated before, it is a “deal”, or a new contract.

However, everyone has different views on how much risk and responsibility they may want to take at different times, and so there should never be any compulsion to do things differently. Personal health budgets can be used, for all, some, or none of someone’s treatment, depending on what that person wants and feels capable of taking on.
If a person is feeling vulnerable, scared and unwell, they may wish for a health professional to determine what is in their best interest. However, over time when they may feel more confident, or if they feel that something vital to them is at risk of being lost or never achieved, they may want to take more control and more responsibility and they may view risk differently.

A more open, trusting and respectful dialogue can lead to better quality decision-making and significant potential for improved outcomes, as someone commits to carrying out the personal plan they have written. This “adherence” is seen as a key component to safety. However, there are workforce development and cultural issues to be addressed:

“Research in the UK suggests clinicians may take a “compliance approach” to self management and this is unlikely to be helpful. The most promising way of supporting self-management appears to involve approaches that empower and activate people so they feel more confident about managing their conditions and are more likely to alter their behaviours. There is strong evidence suggesting that improved self-efficacy is associated with better clinical outcomes.

“Whilst evidence is emerging, there is still a long way to go before we understand the education support necessary to optimise clinician’s attitudes, skills and behaviours towards self management. This also calls for a fundamental shift of power dynamics and the way both patients and professionals view their roles.” 18

- Health Foundation 2011

Supporting staff and people using personal health budgets to find personalised ways of managing risk

When developing the care planning process, it is helpful for both people with budgets and clinicians, commissioners and service providers to work together on how this part of the care plan will be discussed, agreed, and recorded. It can be helpful to have a separate sheet in the care plan that is specifically used to address the issues of risk where the person and anyone supporting them to make their plan, records what might go wrong with the plan and how they plan to minimise the likelihood of this happening.

On this sheet, it can be helpful to have a simple checklist of prompts such as:

- Is there anything that the person or their clinician is worried about?
- Is there anything that has happened in the past that might arise again?
- Is there a possibility of harm or abuse?
- Is there adequate support in place if person wishes to use direct payments to employ their own personal assistant?

In their paper making the case for shared decision making in Health, Coulter and Collins argue that there should be a formal process for documenting:

- The decision
- The agreed course of action
- The on-going roles and responsibility of each party
- The risk- sharing agreement.

18 Helping people help themselves, Health Foundation, 2011.
“While all of the above is usually formalised in the process of consenting to a medical or surgical intervention, healthcare providers should ensure that they have documentation systems and processes in place when there has been a shared decision about any course of action, such as adhering to a medication regime or undertaking a lifestyle or behaviour change. As well as providing a useful record for patients and other professionals they may encounter during their care, this practice could provide protection from legal challenge if clinicians can demonstrate that patients were offered choices and provided with reliable information about the options.”

- Coulter and Collins, 2011

4) Priorities and outcomes

19 Making shared decision making a reality, Angela Coulter and Alf Collins, Kings Fund, 2011.
Implementing effective care planning

Having started with exploring what is working and what is not working, and then going on to consider what is important to and for someone and how the risks will be addressed, some clear priorities will begin to emerge. What needs to be ensured is that all of the priorities and the outcomes which flow from these are the person’s own outcomes. It is important not to add on professionals’ “health outcomes” at the end in the same way that they should not be imposed at the beginning.

“Individual goals need to feel important to the patient - action planning may feel uncomfortable to the clinician where the patient is not willing to agree to something which the clinician sees as important. Engaging with the process is essential to find out what the patient is prepared to do.

“Patients and clinicians have similar aims to improve long term outcomes by increasing length of life and reducing morbidity also in short term improving quality of life; but they often prioritise differently, with clinicians emphasising the former and people with long term conditions the latter.

“Accepting an individual’s quality of life and their knowledge, skills and confidence to manage their own health and healthcare are important outcomes in their own right, poses newer and harder challenges”

- RCGP 2011

If the outcomes are not recognised and owned by the person, then it isn’t their plan and something has gone wrong with the conversation, so there needs to be further dialogue. The prioritising discussion will pull together, from the conversation, what are the joint priorities agreed by the person and the health professional. There will have been a discussion about options, and a clarification of top priorities for action, including risk enablement and contingency planning.

When developing outcomes, care needs to be taken against moving to thinking of services and therapies too soon. Outcomes are not services, treatments or therapy, nor attending places, unless for a specific purposeful outcome. Outcomes are changes in or sustaining of physical behaviours, or mental states/emotions. The care plan needs to describe clearly what is being aimed for and in specific terms: what will be working better, be maintained or be avoided?

This can include what is hoped for even in a deteriorating health condition, or at the end of life.

The health outcomes need to come from the person. The health professional’s role is to help support the identification of the person’s own outcomes and to contribute to making them as specific and individually relevant as possible. The actions that follow are then fully and clearly linked to the specific outcomes.

---

20 Care planning - improving the lives of people with long term conditions, RCGP 2011.
The action planning section of the care plan must specify clearly who will do what and when. It will show who is taking responsibility for each task and how they will do it. For example: “clinician will input particular therapies at frequency agreed, person will purchase equipment and has access to the information of where to get this, and commissioner will check if preferred agency is appropriately registered.”

If someone is planning to employ their own personal assistants to undertake specific health tasks, the plan will state how relevant training will be provided and what process will be put in place for competency to be signed off.

The ideas about the actions to be taken to achieve the outcomes will draw together an individual’s own solutions, which they are committed and motivated to do, with the
health professional’s expertise about what might have proved useful for others and what research evidence suggests too.

The actions in the plan should be specific and linked to the outcomes. As shown above, there must also be clear identification of likely risks and ways to address them. Professionals need to trust people’s own solutions. This is at the heart of the shift in the relationship—people exploring what matters to them and finding their own ways to actively participate in achieving their outcomes.

Effective action planning will produce a set of specific tasks, which form the person’s explicit plan for meeting their health outcomes. These should be integrated with the other key parts of their day-to-day living. It is that personal ownership and control, together with the recognition of health as an interwoven part of someone’s whole life, that enhances the plan’s effectiveness.

6) Sign off

Having my plan signed off by someone who knows me well made the process easy and straightforward.

Ok, we’ve agreed everything now. Can I start organising?

Your plan sounds sensible to me, we just need to agree what will happen if things change.
Since the process of developing a care plan is an ongoing dialogue between an individual and their health team, the plan can often be signed off by the same people who have been part of its development. After family and friends, the health team are often the people who know the family best.

To enable sign off processes remain simple and sustainable, criteria for a good plan need to have been made explicit; and staff need to have had sufficient training and feel confident and trusted to ensure that those criteria for sign-off have been met. The plan may be written in many different styles but it must include the key criteria agreed in the local framework:

Criteria for sign off

1) Show who the person is, with their strengths and skills, and their personal social context, as well as their health needs. If the person lacks capacity to make their own decisions the plan must show how this decision was reached and identify who will speak on their behalf.

2) Describe what is working and not working from their perspective.

3) Detail what is important to the person and what is important for their health.

4) Identify and address any risks and how they will be mitigated to an acceptable level, including a contingency plan for if things go wrong, and a point of contact in health services.

5) State the health outcomes to be achieved and how it is proposed that those outcomes will be achieved.

6) Describe in broad terms how the money will be held and managed and show how it will be used to achieve the outcomes.

7) Have an action plan that details who will do what and when to ensure that the plan is carried out.

8) Include the name of the person’s care coordinator.

9) State how and when the outcomes, and the money, will be monitored and reviewed. This will include describing how people will know the plan is going well, and how people would know if things were going wrong.

Ideally, sign-off is delegated to a person that is as close to the individual as possible, in line with the NHS principle:

“Personal health budgets must support the making of decisions as close to the person as possible. In this way, it is a decision made by health professionals who are closely involved and know the person and their unique family and community context.”

- The Department of Health

Alongside training and good working knowledge of the criteria, risk enablement processes can be helpful, so that no single professional feels that they must make decisions alone. These processes allow health professionals, individuals and family members to

21 Personal health budgets: first steps, the DH 2009.
bring together a small, consistent group of people familiar with health risk enablement, to consider a particular risk – should they wish to do so. The group agree how best it will be managed and record that learning. Over time, a log of risk enablement strategies are gathered that can then be a helpful local resource, and a source of national good practice.

Authorisation processes will need to respect the fact that peer network members are clear about decision making processes. They expect to be present when all decision-making takes place, along with whomever else they may wish to support them. If a plan cannot be signed off, then clear guidance for how it needs to be amended should be given.

Appeals

It is necessary for all parties to know what will happen if there is disagreement, and to have a clear process of appeal.

7) Review the plan
Monitoring and reviewing processes must be evolved to match the fact that for many people with long term health conditions, they must regularly self monitor, review and act to address changes in their health condition. As outlined above, a well-written plan will include information from the relevant health professionals about the person’s particular critical health factors, and how these must be addressed. The plan will also state what actions to take when necessary to address a change in these critical factors, and who to turn to if things go beyond a specified safe limit.

The frequency of reviews should be sensitive to each person’s unique situation and health condition. Individuals with personal health budgets will need to be fully aware that they do not have to wait for a scheduled review if their circumstances or health condition have significantly changed, but can call for a review as necessary.

The formal review of an individual’s personal health plan will be a summary reflection of the micro reviewing and monitoring that is taking place by the individual personal health

I’ve taken control. My personal health budget has helped me feel well and given me back my self worth.

It’s going really well. You could have done it all for me, but making decisions and doing it for myself has given me my life back.

That’s great. Let’s meet for your next review in 3 months... and do come back if anything suddenly changes.
budget holder, (or their family carer), who holds this responsibility every day. The purpose of the review should be clear and explicit and planned to make the best use of everyone’s time. There should be no surprises, since through the year the person can alert their health professional and call a review if there are any critical incidents or crises. Similarly, a proportionate and simple monitoring of the budget will have been on-going through the year, and can be summarised for review.

Department of Health regulations for personal health budgets direct payments state that there must be a care coordinator to fulfil the following functions:

- Manage the assessment.
- Ensure people have an agreed care plan.
- Manage the review and monitoring process and liaise between the NHS commissioning organisation and the person receiving the direct payment.
- When someone is not receiving the budget as a direct payment, having a named point of contact to carry out each of these functions is equally valid and necessary.
6 Conclusion

Personal health budgets can be transformative, efficient and effective. Their quality and effectiveness can be locally evaluated, in an on-going way, by putting in place simple feedback mechanisms to assess their impact from the perspective of people themselves, health professionals, provider organisations and commissioners.

It is helpful to see a personal health budget as one useful tool or mechanism, which on its own is not sufficient to achieve useful change. The budget is however, an important lever to support the changing relationship between people and professionals and to enable effective planning and innovation. The local framework contains the essential elements to making personal health budgets care planning work well. And the care planning process itself is at the heart of the shift in power, to ensure that people with long term health conditions and disabilities have the chance to shape their lives by making the decisions about their health and wellbeing that matter most to them.

The personal health budget planning process encourages “blue sky” creative thinking, and is unconstrained by existing services.

It seeks to find the right way forward for the individual. If carried out successfully and supported at an early stage with an indicative budget, this can be a therapeutic and enlightening process. We all know that planning alone can be an isolating and frustrating process, but when done collaboratively, exciting solutions can emerge that make a real difference to people’s lives.

“Having a personal health budget allows people to have a real say in how their future should look. It allows them to work with people they trust to deliver their support when they need it and how they need it. It allows Personal Assistants to develop skills that are directly relevant to the individual’s needs. It allows for flexibility and is adaptable to changing situations. It allows people to move from a world where others know best to one where their input is valued above all others but not in isolation from others”

- Personal health budgets peer network member
Appendix 1
Questions from workshops

Questions pilot sites found helpful to have considered prior to offering personal health budgets to individuals

Knowing the deal includes some pivotal issues for which it is critical to have at least workable tentative answers before offering people personal health budgets even if they do not all need to be fully resolved before starting the process. Sites were asked to convene a meeting with roughly equal representation from people interested in or using personal health budgets, clinicians, commissioners and finance staff. For each of the five bundles of questions below, they considered their local answers to these three questions:

1) Is there a shared and commonly agreed answer? OR

2) Do people have a variety of views? OR

3) Have we not yet developed an answer for some of these questions?

What is this all about?

- How do I find out about personal health budgets?
- Where did this idea come from?
- Is it about saving the government money?
- Is it about privatising the NHS?
- What is a personal health budget – is there a definition?
- What are they for?
- What is the purpose of them?
- Is it about just more choice or is it about changing the relationship between people and the NHS?
- When is a personal health budget offered to me?
- Is it only offered once and can I change my mind?
- Do I have to have one?
- Can I keep things how they are?
What are the “rules” around the money?

- What can the money be spent on?
- What can it not be spent on?
- How is the amount of money I can have control of, worked out, and for how long is this put in place?
- When do you tell me how much money is available to plan with?
- Can I have help with holding and managing the money?
- Can everyone have the money given directly to them, and if not what other ways can I still have control of the decisions while someone else holds the money on my behalf?
- What do you expect of me, in terms of keeping records?
- What can I expect of you in terms of flexibility in using the money, and keeping the processes simple and trusting me to use the money well?
- Is it paid monthly or yearly?
- Can I save some for contingencies/emergencies, or do I have to pay back anything under-spent each month?
- What happens if I spent too much, or too little?
- What happens if I make a mistake?

- What if my needs change – is there an opportunity to have more money if I become more unwell or does it stay the same for the year?
- Do I have to “cash in” every part of my Health funded care or can I just choose to control the things that matter most to me?
- Can I have a mix still of NHS services and some things which I buy for myself?

What about how to create my plan?

- What are the local criteria for agreeing any care plan – and have I seen these so I can write my own plan?
- Who explains about what a care plan is for and what needs to be included in it?
- Do I need separate plans for social care and health money?
- Is there a booklet or guide I can read to tell me about what I have to do?
- Can I talk with someone else who’s done this before?
- Are there any examples of what others have done?
- Who can help me with this plan?
- Does it have to fit into a predesigned form?
- What is an outcome?
- How do I keep myself safe?
- If I want to employ staff what help can I have with that?
Implementing effective care planning

- How will we agree the skills and competencies needed for any staff and what training they should have?
- Who will support my staff and agree rotas and manage payroll, sick pay, and holiday cover?
- Can I have help to find the things and the kind of people I want?
- How much control will I have?

**How is the care plan agreed?**

- Who “authorises” or agrees the plan, where are the decisions made and do they have to tell me, if it has not agreed, why that is the case?
- How long do I have to wait till I know if my plan has been agreed?
- Can I keep my own copy?
- How can I let you know my wishes if I cannot express myself easily?
- What if I’m not able to make decisions for myself- who will speak for me?
- Where does the buck stop – whose responsibility is all of this – mine, yours or ours?
- Is it now always about me knowing best, or is this a shared agreement between expert professionals and me?
- If we cannot agree, who makes the final decision?

**How is the care plan reviewed?**

- How will we know if it is working well?
- What happens if what I planned does not work out, and who can I call if I am worried?
- Is it ok to try some things and fail?
- How often will reviews happen and who can call one?
- Whose perspectives are considered?
  (Mine/health professionals/family carers/social care professionals/commissioners/finance staff?)
- Will we focus on whether the outcomes have been achieved, or what has been bought?
- Will there be a separate process for reviewing the money or will we have one process to consider both money and outcomes together?
- Are local people involved in developing the local care planning process alongside health professionals, and commissioners from health and social care?
Appendix 2

How peer support can help

Peer support can:

- Help someone begin to feel hopeful and begin to see that some things could change for the better, even in the most challenging situations.
- Help someone dare to say what’s not working well, and so consider priorities for change.
- Let someone hear ideas about possible alternative ways of achieving health outcomes. For example, how can someone choose red or green if the only colour they have ever seen is blue? How can someone know that there are other ways to meet people, learn and have fun outside of a segregated day care centre?
- Allow someone to learn from others’ direct experience.
- Enable someone to plan at a pace that feels comfortable to them.
- Let someone be supported to decide how they may want to have the money held and managed after they have thought about everything they want the plan to achieve and not be rushed into choosing a direct payment or any other option until they’ve understood what it means.
- If they choose a third party to hold the money, peer support can help them to consider the things to beware of and to look for in a third party organisation so that they can retain the amount of control that they want.
Implementing effective care planning

Appendix 3
Risk enablement example

Merseyside Mental Health personal health budgets pilot Recovery Enablement Panel draft terms of reference

“It is anticipated that the large majority, if not all, cases involving Personal Health Budgets will be agreed and implemented at the multi-disciplinary assessment and care planning stages of the Care Programme Approach and that referral to the Recovery Enablement Panel will be exceptional.”

Introduction

Members of the Merseyside Mental Health Pilot (NHS Sefton, NHS Knowsley, Liverpool PCT and Mersey Care NHS Trust), recognise that risk can be a consequence of people taking decisions about their lives. These Terms of Reference describe the arrangements that the Merseyside personal health budget Pilot has put in place to manage what are deemed to be high risk or complex situations and to support people on the road to recovery.

To make good choices, we all need to understand the consequences of the decisions we make and to take proportionate responsibility for them. The Merseyside personal health budget Pilot aims to promote a culture of choice that entails responsible, reasonable, supported and shared decision-making.

Reasonable risk means striking a balance between empowering people to make choices, whilst still supporting them to take informed everyday risks.

The Recovery Enablement Panel will share decision making in situations considered to be of higher risk, with the aim to mitigate the risk in an effective transparent and safe way based on the information available.

The Recovery Enablement Panel will provide a forum to consider identified risks and mitigating actions in the small minority of cases where these cannot be satisfactorily resolved during the normal processes of multi-disciplinary assessment, support care planning or review as supported by the Care Programme Approach.

Risks can be physical or emotional, by or to the service user or others, linked to the capacity or capability of individuals or organisations, reputational and/or linked to service cost or type.
Purpose
The purpose of the Recovery Enablement Panel is to:

- Guide, advise and support staff, service users and their carers to ensure that risks with potential high repercussions are managed and minimised to protect staff, service users and the organisations involved. The Panel has been designed to be a safe and supportive environment for both the individual and staff.
- Ensure a consistent and enabling approach to managing risk decision-making, where the risk to independence is balanced with the risk of ‘not supporting choice’.
- To seek positive solutions and outcomes for individuals and resolve issues relating to the sharing of risk between individuals, third parties and the NHS organisations.
- To ensure that no individual is left to make a difficult decision without support and that NHS organisations involved in the Pilot can demonstrate they have fulfilled their duty of care in the support of service users and staff.
- To provide a forum where staff at different levels in the organisations and service users can share risk decision-making where there is raised concern over levels of risk.
- To take the final decisions on issues involving risk or complex issues which member of staff, service users or others refer to the Panel.
- To promote a consistent approach to managing complex risk decision-making.

Scope of Responsibility
It is anticipated that the large majority, if not all, cases involving personal health budgets will be agreed and implemented at the multi-disciplinary assessment and care planning stages of the Care Programme Approach and that referral to the Recovery Enablement Panel will be exceptional.

The Panel will act as decision maker for cases referred. It will explore, with the clinicians involved in the case, how the risk may be mitigated and managed to promote recovery and advise the clinicians accordingly. Decisions to proceed with support packages, based on the guidance of the Panel, can only be sanctioned by unanimous agreement of the Panel.

It is the responsibility of the care team and management to implement the decisions of the Panel.

The Recovery Enablement Panel will liaise with the personal health budget Steering Group and the relevant NHS organisation regarding any issues arising from the management of complex risk cases.

The Recovery Enablement Panel will not consider complaints arising from the refusal of Primary Care Trusts or Mersey Care to fund cases found not to meet the relevant eligibility criteria for funding or service provision. Each NHS organisation has separate procedures for dealing with such complaints.

The Recovery Enablement Panel will not replace or substitute existing processes and procedures such as safeguarding and complaints where it is more appropriate to use these.
Referrals to the Recovery Enablement Panel

Referrals to the Recovery Enablement Panel should be made to the Steering Group representative of the relevant Primary Care Trust (Panel Convenor) a minimum of seven working days before a decision is required.

Referrals may be made, in writing, by the service user, carer, clinician, Primary Care Trust Panel Manager, broker, peer support worker, project manager and members of the Steering and Project Groups.

The Recovery Enablement Panel will consider referrals on the grounds of risk directly related to the use of a personal health budget:

- Physical or emotional risk.
- Anticipated risk to or by others.
- Political or reputational risk to the NHS organisations or partners.
- Financial or budgetary risk that cannot be addressed through existing NHS processes.
- Legal or regulatory issues.

The Recovery Enablement Panel may refer to other organisational processes or seek advice where this is considered appropriate.

Suitability criteria

The Recovery Enablement Panel will determine a service’s suitability by ensuring that the proposed intervention fulfils the following criteria:

- The proposed service will help work towards specific longer term outcomes identified in the service user’s Care Plan and specifically, the service user’s agreed outcomes.
- The proposed service represents a reasonable balance between risk and empowerment.
- The service user is realistically likely to engage with the service.
- The proposed service is legal.
- The proposed service is directly or indirectly related to the service user’s core condition.
- The proposed service has been chosen following consultation with family and/or carers where appropriate.
- The proposed service will not pose a major risk to the PCT or Trust (e.g. adverse publicity, legal action).

Membership

The Recovery Enablement Panel will comprise a minimum of 5 from the following:

- Team manager (Chair).
- Care co-ordinator (from a different team).
- Primary Care Trust representative.
- Mersey Care representative.
- Project Manager.
- Clinician responsible for the support package.
- One or two independent service users (one could be a supporter of the other).
- The service user (or representative).
- Finance representative of the relevant Primary Care Trust.
The Panel may invite relevant others, i.e. Primary Care Trust Panel Manager, Communications lead, broker to join the Panel as appropriate. Where a Panel member cannot attend they may nominate an appropriate deputy or submit written comments.

A quorum will be five members. This must include the team manager, the clinician responsible for the support package and the PCT and/or Mersey Care representative as appropriate.

**Frequency and format of meetings**

Each Panel will have a designated chairperson to ensure accountability, continuity and commitment. The chairperson will normally be the Team Manager of the accountable team.

Panels will meet as appropriate to the needs of the personal health budgets pilot. There is no set frequency for meetings; they will be convened as the need arises. All paperwork should be with the Panel Convenor at least seven days before a decision is required.

Panel meetings should be well documented and decisions accurately recorded to clarify outcomes and allow actions to be demonstrated. The Panel may set review dates to satisfy itself of the continuing efficacy of the agreed care plan.
Gateway Ref No. 17753

Personal health budgets team
Websites: www.personalhealthbudgets.dh.gov.uk/toolkit
Email: personalhealthbudgets@dh.gsi.gov.uk
Department of Health customer service centre: 020 7210 4850